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Adults with Disability:
Care Network Characteristics and Outcomes

by

Pamela Berry Otfinowski

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Science

in

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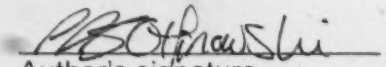

Author's signature

3831-117 St.
Edmonton, Alberta T6J 1S8

Date submitted: Jan. 28, 2003
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Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled ***Adults with Disability: Care Network Characteristics and Outcomes*** submitted by Pamela Berry Otfinowski in partial fulfillment of the requirements for the degree of Master of Science in Family Ecology and Practice.

Dr. Janet Fast
Supervisor

Dr. Norah Keating
Committee Member

Dr. Priscilla Koop
Committee Member

January 27, 2003
Date thesis is approved by committee for submission to Faculty of Graduate Studies and Research, University of Alberta

ABSTRACT

The study examined the characteristics and outcomes of family and friend networks providing care to adults with disability in order to inform caregiving policies and research that traditionally have focused only on care dyads not care networks, network support not care, and care to children or seniors but not adults.

The 1996 Canadian General Social Survey provided a sample of 187, 18 to 64 year olds who, because of their long-term health or physical limitation, received help from family, friends or neighbors. Care networks had a mean size of 1.6 and primarily comprised women, kin, members aged 25 to 64, and living close-by. Adults with disability who were in good health, or who had large networks, were provided the greatest amount and variety of care while those most at risk for inadequate care were those already in poor health or those with networks that were small or without proximate members.

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For Olaf and Cassian

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CHAPTER ONE
INTRODUCTION

"Unless there are formal supports for unpaid caregiving, both the caregivers and their relationships are increasingly likely to fall apart. And such supports need to recognize the diversity in needs and the diversity in networks, networks that extend beyond kin to create the most satisfying care" (Armstrong & Kits, 2001, p. 20).

Background of Inquiry

The number of Canadians requiring care over a significant portion of their lifespan is growing steadily due to advances in medicine and technology that have improved the survival rate and longevity of young individuals with congenital, chronic or traumatically acquired illness or disability (Allen & Mor, 1997; Kahana, Biegel & Wykle, 1994). The question of who is responsible for the care of these individuals, as well as increasing numbers of frail older adults, (Fast & Keating, 2000), recently has been a focal issue of debate at both the Federal judicial and legislative levels (Fast & Keating, 2001; Tibbets, 2001). The debate has arisen in the wake of an eroding government social safety net evidenced by continued public sector cutbacks, and philosophical shifts emphasizing greater family and individual responsibility for care (Brodie, 1999; Crichton & Jongbloed, 1998; Keating, Fast, Connidis, Penning & Keefe, 1997; Nolan, Grant & Keady, 1996).

Care provided in the community by family members, friends or neighbors, sometimes referred to as informal care, typically is unpaid and provided with little or no formal training (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Statistics from the early 1990's, showing that over half of the of 4.2 million Canadians living with a disability were both living in private households and between the ages of 14 and 64 (Crichton & Jongbloed, 1998; Federal, Provincial and Territorial Ministers (FPTM) Responsible for social services, 2000) suggest that family and friends likely already have provided a substantial amount of care to this population.

A key assumption of current health care policy is that individuals with disability are surrounded by networks of family and friends who should and will

provide them with care when needed. Formal services are viewed as merely supplemental, with access to them commonly based on assessment of family and friend, or "informal," care network resources (Harlton, Keating & Fast, 1998; Home Care Development Canada, 1999). Policy documents suggest that care provided by such networks is more cost effective (Federal, Provincial, Territorial Working Group on Homecare, 1990, Harlton et al, 1998; Keating et al., 1997) as well as more appropriate because it is based on shared history, values, loving relationships (Phillipson, 1997; Fast, Williamson & Keating, 1999) and normative obligations to provide care (Cantell, Bruhm & Lilley, 1998; Aronson & Neysmith, 2001).

However, critics of current health and continuing care policy argue that the costs of providing care to individuals across the lifespan simply have been shifted from the formal sector to networks of family and friend caregivers in the community (Myles, 1991; Fast et al., 1999). In addition, social and policy changes have prompted concern about the ethics of increased reliance on networks of family and friends (Post, 1988), their normative obligations and ability to provide long-term care, and about the safety and quality of care provided (Armstrong & Kits, 2001; Fast & Keating, 2000). These changes include, for example, significant economic and non-economic costs incurred by family and friend caregivers, greater sophistication of in-home care, increased female workforce participation, smaller, more diverse and mobile families and few, inconsistently accessible and narrowly targeted polices to support either family/friend caregivers or working-aged individuals with disability (Armstrong & Kits, 2001; Eales, Keating & Fast 2001; Fast & Keating, 2000; FPTM, 2000; Phillipson, 1997). In light of current trends, the sustainability of long-term reliance on family and friend care networks is brought into question (Health Canada, 1999; National Advisory Council on Aging, 1999).

Unfortunately, current research is limited in its ability to substantiate assumptions or concerns about the capacity, effectiveness or even the existence of care networks providing care to young or middle-aged adults and others with long-term care needs. In Canada, the development of both research and

services targeting younger adults with disability and their caregivers has been limited, is currently outdated (FPTM, 2000) and, when available, tends to focus on narrow categories of disability such as intellectual disability (Salvatori, Sandys & Marcaccio, 1998).

It also is difficult to draw inferences about the care networks of working-aged adults from the substantial bodies of literature on caregiving to seniors or children with health limitations or disability. Few studies actually take either a network approach (Fast & Keating, 2000) or a lifespan approach to caregiving (Kahana et al., 1994; Nolan et al., 1996) while others present contradictory findings about the similarities or differences between caring for people in different age groups (Altman, Cooper & Cunnigham, 1999; Haveman & van Berkum, 1997). Thus, there are limited empirical data to inform policy regarding the care networks of young and middle-aged adults or to support or refute the argument that similarities exist between older and younger age groups in the study of disability issues such as reliance on family or friend caregivers (Kennedy & Minkler, 1998).

A lack of information has resulted in poor understanding of the capacity of family and friend care networks, their need for supports and services and how to target them. It has been argued, however, that the development of well-targeted support measures is required to avoid crises and the need for more expensive interventions for both people with disability and their family and friend caregivers (Chappell, 1993; FPTM, 2000). This study addresses some of the questions arising from the limitations of current research and policy assumptions about family and friend care by conducting an investigation of care networks and the care these networks provide to young and middle-aged adults who have long-term care needs.

Purpose of Study

The purpose of this research is to examine empirically the characteristics of care networks of young and middle-aged Canadian adults with long-term health limitations or disability in order to better understand their functioning and capacity to provide different kinds and amounts of care. This examination will

include description of the size and composition of care networks for this adult age group. The influence of network characteristics on the kinds and amount of care provided then will be explored. This study will provide a foundation for future examination of the formation, function, capacity and support needs of different kinds of care networks as well as of the unmet needs of care-recipients.

Justification

Contradictions are prevalent within current health care policy and between policy and research regarding the long-term care needs of young to middle-aged adults with disability. On the one hand, policies acknowledge the growing care needs in the population and emphasize continued and increasing reliance on family and friend networks to provide care to individuals across the lifespan. On the other hand, policies direct few resources to support care networks thus placing their sustainability at risk.

Existing research and policy measures tend to be narrowly focused on individual or primary caregivers, close family caregivers and those providing care to children or older adults. For the most part, existing research and policy do not target care networks or non-kin caregivers and rarely focus on caregivers of young and middle-aged adults. These oversights persist despite a call from disability advocates to provide support to family and friend caregivers in order to assist people with disability to participate actively in their communities (FPTM, 2000).

What we know about family and friend caregivers of individuals in different age groups, and the consequences caregivers experience, is based primarily on information about pairs of care-receivers and their primary (usually close family) caregivers (Boaz & Hu, 1997; Keating et al., 1999; Lefley, 1997). The previous, predominantly dyadic, approach to caregiving research has resulted in a poor understanding of how larger networks of individuals may work together to provide care. Furthermore, the impact of different configurations of caregivers on care provided, such as all kin versus a mix of kin and non-kin, is not well understood (Fast & Keating, 2001). This gap exists despite the fact that up to 20% of caregivers in the community are non-kin (Keating et al., 1999) and that

the emphasis on non-kin members in care networks is expected to increase due greater incidence of divorce, remarriage and low birth rates affecting smaller, more diverse and less stable family structures (Himes & Reidy, 2000).

Finally, while there is a body of literature in which networks are the unit of analysis, previous research primarily has targeted larger social groups and the exchange of information or support rather than the provision of care or assistance provided specifically because of the recipient's health or physical limitations (Keating et al., 1999). Some preliminary information about the function of care networks can be gleaned from studies of support networks that describe different health and formal service utilisation outcomes by support network type (see, for example, Litwin, 1997A, 1997B; Wenger, 1991, 1994, 1997). For the most part, however, these studies are focused on older adults and interpretation of their findings must be applied cautiously to the study of networks providing care to young and middle-aged adults.

There is a paucity of information about care networks overall, and about those caring for working-age individuals with long-term care needs specifically, despite a growing reliance on both. An empirical examination of network characteristics and their influence on kinds and amount of care tasks provided is a first step in understanding the functioning, capacity, resources and support needs of care networks as well as the impacts (positive or negative) of evolving public policy and practice related to the care of young to middle-aged adults with long term chronic illness or disability. Thus, this research will help to bridge gaps in knowledge about family and friend care, examine existing contradictions and inform potential collaboration between researchers and policymakers from both disability studies (primarily focused on 'working-aged' or younger adults with disability) and gerontology (Fast & Keating, 2000; Haveman & van Berkum, 1997; Salvatori, Sandys & Marcaccio, 1998). Based on this preliminary analysis, future research can focus on how outcomes and support needs differ between care-receivers and among care network members belonging to different kinds of networks.

CHAPTER TWO
THEORETICAL FRAMEWORK and REVIEW of LITERATURE

This chapter provides a review of literature that informs the questions of what are the likely characteristics of family and friend networks caring for young to middle-aged adults with disability and how will these characteristics influence the types and amount of care provided. The literature also will be examined for factors that may affect variation in care network characteristics and outcomes across such a broad target population.

The review of literature follows a brief overview of the socially defined and influenced nature of disability and caregiving. Both discussions are guided by a theoretical framework based on Symbolic Interaction theory, which focuses on meanings created and ascribed to relationships during the course of social interaction (LaRossa & Reitzes, 1993).

According to the World Health Organization (WHO), disability is "any restriction or inability to perform an activity in the manner or within the range considered normal for a human being," while a handicap is a disadvantage, "resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal for the individual" (FPTM, 1998, Appendix A). Care is assistance or help provided to someone because of their long-term health limitation or disability (Keating et al., 1999) and a care network is the group of family, friends and neighbors that provide that care (Keating, Otfinowski, Wenger, Fast & Derksen, in press). Overall, perceptions of handicap and the taking on of social roles, such as care-receiver or care network member, are influenced by social interaction, social norms and cultural context (Chiriboga, Ottenbacher & Haber, 1999; Pescosolido, 2001; FPTM, 1998). It is important, therefore, that the influence of social interaction is explored in a review of literature examining the important characteristics of networks providing care to people with disability.

Symbolic Interaction theory and related concepts, which focus on meaning and motivation for behavior arising in the process of social interaction (LaRossa & Reitzes, 1993), are used to identify important care network

characteristics and the likely configurations of those characterisitcs. This is followed by a discussion of the potential influence of network characteristics on care outcomes including the kinds and amount of care provided. Hypotheses about care network characteristics and outcomes then are developed for empirical testing.

Theoretical Framework

An assumption of Symbolic Interaction theory is that, through shared symbols and meaning, social interaction influences the perceptions and behavior of individuals towards others, specific issues or events, such as caregiving. More specifically, it is through the salience of identities within social roles that individuals develop a sense of self and their motivation for behavior (LaRossa & Reitzes, 1993). Furthermore, socially influenced meanings and motivations are not static but can change over time and in different contexts (LaRossa & Reitzes, 1993). Motivation to provide care to a young or middle-aged adult with a disability is the main focus here. By examining the meanings commonly ascribed various social roles and how they may be affected by the presence of disability and the need for caregiving, Symbolic Interaction theory helps to elucidate motivations for care network membership based on the nature of prior relationships.

According to Symbolic Interaction theory, roles are shared norms or meanings associated with different social positions that function to create expectations of social behaviour between the individual who occupies the role and others (LaRossa & Reitzes, 1993). Normative expectations of behaviour, assigned to different social roles in the course of social interaction, are key to understanding which kinds of social relationships typically define the characteristics of care networks. In addition, understanding the circumstances under which social roles and associated expectations can be flexible may help to explain the occurrence of less typical care network characteristics.

Everyone is embedded within a large network of social relationships. However, the nature of the social role associated with many of those relationships often is impersonal with expectations primarily for information

transmission (Lubben & Gironda, 1996). Other social relationships, however, have potential to transition into a supportive role with expectations to participate in exchanges of support and to form a support network subset of an individual's social network (Israel & Antonucci, 1987; Langford, Bowsher, Maloney & Lillis, 1997; van Tilburg, 1995; Walker, Wasserman & Wellman, 1994). Some, but not all, individuals in supportive roles further are ascribed expectations to take on a caregiving role, or to become members of a care network, for those that require continued or enhanced support because of limitations caused by ill health or disability (Harlton et al., 1998; Nolan et al., 1996; Walker, Pratt & Eddy, 1995).

From a Symbolic Interaction perspective, several key concepts help to explain how the nature of some supportive social roles fosters expectations for involvement in a care network. These concepts, including social capital, embeddedness, reciprocity and normative expectations, further help to elucidate the defining characteristics of care networks (Keating et al., in press).

Social capital is a concept that embodies the potential of social roles to provide support or care (Hibbard, Neufeld & Harrison, 1996; Oxman & Berkman, 1990) as it reflects the number of social relationships in which an individual has invested, maintained over time and developed expectations for exchange of resources (Tijhuis, Flap, Foets & Groenwegen, 1998). Reciprocity is the mutual exchange of support or resources between individuals (Langford et al., 1997; Levitt, Weber & Guacci, 1993) that can be specific or general in kind, immediate or delayed over time or even over the life course (Ingersoll-Dayton & Antonucci, 1988; Litwin, 1998; Walker et al., 1994).

A history of long-term supportive, reciprocal relationships can create expectations for care network membership (Keating et al., in press) because it fosters a sense of moral obligation to provide care (Phillipson, 1997), or because the provision of care is a way to repay prior acts of support (Ingersoll-Dayton & Antonucci, 1988). Having few supportive reciprocal relationships, or poor social capital, may limit the number of potential caregiving relationships and, therefore, care network size. Because having inadequate care resources can put

individuals with disability at risk for poor health outcomes and institutionalization (Pescosolido, 2001), size is an important characteristic of care networks.

Other aspects of social relationships influence the development of reciprocity, the build-up of social capital and, thus, expectations for care network membership. These aspects potentially influence not only the size but also the composition of care networks and include a sense of emotional embeddedness or connectedness (Bernard, Johnson, Kilworth, McCarty, Shelley & Robinson, 1990; Bowling, Farquhar & Browne, 1991; Langford et al., 1997; Levitt et al., 1993) and normative social role expectations for supportive or caring behavior (Cambell, Connidis & Davies, 1999; Magdol, 2000).

Embeddedness develops over time and is most typical of close kin relationships because they tend to be of long duration (Bernard et al., 1990). However, a sense of embeddedness also may develop among non-kin who have maintained a long-term relationship, perhaps in the absence of close kin relationships. Therefore, under some circumstances, individuals in a non-kin social role may be ascribed expectations for care network membership that are most commonly associated with a kin social role (Barrett & Lynch, 1999).

According to Symbolic Interaction theory, some social roles have greater normative expectations for certain kinds of behavior than others. For example, both kin social roles and female gender roles possess greater expectations for providing care, overall, than other social roles (Levitt et al., 1993; Lubben & Gironda, 1996; Walker et al, 1994). Gender and relationship roles also are prescriptive when it comes to the provision of specific kinds of support and care tasks (Ajrouch, Antonucci & Janevic, 2001), such as female kin being most likely to provide help with housecleaning or meal preparation. Because gender and relationship are prescriptive of normative expectations for the provision of care, relationship and gender composition are important characteristics of care networks.

Social roles also can change over time (LaRossa & Reitzes, 1993). For example, changes in physical abilities and social demands as individuals age

can influence their ability or willingness to take on social roles such as participation in care networks or particular care tasks (Litwak, Jones Gessop & Moulton, 1994). Thus, the age composition of care networks may be an important characteristic.

Density and geographic proximity are two additional characteristics of care networks that are important for consideration. Density, or the amount of contact or familiarity among individuals, is a way to examine the embeddedness of relationships. Density can be useful to examine the motivations of less typical care network members, such as extended kin or non-kin, who may over time have developed a reciprocal relationship with the person with a disability (Bowling et al., 1991; van Tilburg, 1998) and expectations for caring behavior.

From a distance, the efficiency, accessibility and diversity of modern communication may facilitate reciprocity and maintaining a sense of connectedness that fosters the development of density and expectations for care network participation (Keating et al., in press). A heightened sense of embeddedness, however, likely is facilitated by more direct or face-to-face interaction and exchange that require geographic proximity. Furthermore, geographic proximity is essential for provision of certain kinds care, especially frequently required instrumental or "hands-on" type tasks (Israel & Antonucci, 1987; Tijhuis et al., 1998).

Using Symbolic Interaction theory, the nature of different social roles and shared normative expectations for motivating supportive or caring behavior and potential care network membership, were discussed. In summary, it seems likely that size, relationship composition, gender composition, age composition, density and proximity are key care network characteristics to examine for their influence on kind and amount of care to be provided.

Care Network Characteristics

The following review of literature examines what is known about each of the care network characteristics listed above and their potential influence on care outcomes. Due to the paucity of existing information about care networks,

additional information for the review is extrapolated from the literature on support networks, care provided to other age groups and care dyads.

Size

As described in chapter one, there is increasing demand on family and friends to provide care for young and middle-aged adults with disability due to their greater numbers and policy shifts emphasizing family and friend care (Allen & Mor, 1997; Armstrong & Kits, 2001). However, researchers have described several potentially negative influences on care network participation. These include disincentives such as social stigmatization of people with disability and those associated with them, absent or poorly accessible supports or compensation for family and friend caregivers (Crichton & Jongbloed; 1996) and increased complexity of care (Allen & Mor, 1997; Fast & Keating, 2000). At the same time, there are noticeable trends towards decreased family size, more women in paid employment and greater individual and family mobility potentially limiting the availability and proximity of traditional family/friend caregivers (Fast et al., 1999; Phillipson, 1997).

Disability that impacts ability to interact socially also may result in poor care network participation and overall size. For example, disability that is severe and/or acquired at an early age may limit opportunities or ability to invest in a career and build up financial capital, or to invest in reciprocal, long-term relationships and build up social capital (Tijhuis et al, 1998; Walker et al, 1994). As a result, individuals with disability may have limited potential to initiate or sustain relationships that result in care network membership if they have limited social capital to start with or if they are unable to contribute to the infrastructure, financial and other costs demanded by the caregiving situation (Allen & Mor, 1997; Litwak et al., 1994).

From the caregiver perspective, negative perceptions of burden or interference with career or family ambitions associated with expectations for long-term or even life-long caregiving, can limit care network participation (Allen,1994; Litwak et al. 1994; Twigg & Atkin; 1994). Additional disincentives to care network membership include the physical maturity of adult care-receivers

that can make their care physically demanding and the personal nature of some care tasks that may be perceived by some as a violation of societal incest and privacy norms (Litwak et al., 1994). Parenting and socialization norms may also be contradicted, incurring social stigma, by non-normative needs to care for a mature young to middle-aged adult (Schieman & Turner, 1998; Wenger et al., 1996; Williamson, 1998).

Overall, a review of current literature suggests that there are several factors that may negatively influence care network participation and that, for the most part, care networks will be small. One study of the care networks of adults with mental illness found an average size of 1 to 4 with a significant proportion having only one member (Tausig, Fisher & Tessler, 1992). Studies of seniors' care networks have found average sizes of 3 to 5 members (Tennstedt, McKinlay & Sullivan, 1989) and 1 to 2 members (Fast, Derksen, Keating & Otfinowski, in review).

Studies of seniors' care networks have found that larger networks are associated with a higher probability of receiving help with meal preparation, house cleaning and banking and bill paying as well as receiving more hours of care, overall (Derksen, Fast, Keating & Otfinowski, 2002; Fast et al., in review; Penrod, Kane, Kane & Finch, 1995). In terms of the adult population of interest to this study, it generally is agreed that larger care networks have potential to provide greater amounts and more kinds of care while small care networks may put young or middle-aged adults at risk for inadequate care resources or gaps in care (Grant & Wenger, 1993; Pescosolido, 2001). Larger networks also likely require enhanced coordination of care resources (Pescosolido, 2001).

Younger adult care-receivers may tend to have smaller care networks than those closer to middle-age because they will have had less time to develop additional close or long-term relationships (Grant & Wenger, 1993; Litwak et a., 1994; Tausig et al., 1992). One study also found that care-receivers in poorest health tend to have the smallest care networks (Litwin, 1997A).

Gender Composition

Historically, there always have been greater normative expectations for women to provide care for people with disability of any age (Hirsch, 1996; Tausig et al., 1992) although studies suggest a significant minority of caregivers are men (Keating et al., 1999; Klein Ikkink & van Tilburg, 1998). Indeed, despite being more likely also to be in paid employment than ever before (Armstrong & Kits, 2001; Phillipson, 1997), women continue to provide the bulk of unpaid care and are still most likely to be care network members (Grant & Wenger, 1993). Potentially, the extent or sustainability of contemporary female care network involvement may be limited due to time constraints or burnout related to conflict with work, although women are more likely than men to reduce or quit work to provide care overall (Armstrong & Kits, 2001). In addition, several studies suggest that women tend to attribute more personal meaning and salience to caregiving, making them more likely to take on care network roles or to provide greater amounts of care to young or middle-age adults with disability (Tausig et al., 1992; Twigg & Atkin, 1994; Wenger, Grant & Nolan, 1996).

Overall, care networks are most likely to have high proportions of female members. Evidence also suggests that women, and thus networks with a higher proportion of women, will provide more hours of care than men (Fast et al., in review; Klein Ikkink & van Tilburg, 1998;Tausig et al., 1992). However, kinds of care tasks tend to be differentiated by gender (Keating et al., 1999). For example, one study of seniors' networks found that care networks with high proportions of women were more likely to provide tasks traditionally associated with female gender such as meal preparation, housecleaning, grocery shopping and personal care. The study also found that female dominated networks were associated with a higher probability of receiving help with banking and bill paying but a lower probability of receiving help with home maintenance (Fast et al., in review). Home maintenance and transportation are tasks that other literature suggests are more likely to be provided by men (Grant & Wenger, 1993).

As a result of gender specific expectations for care, young and middle-age adults with disability may not receive enough care if their networks do not

possess sufficient female membership, or they may have gaps in care if their network does not possess sufficient gender diversity. For example, the literature suggests that the care networks of young adult child and male care-receivers often primarily comprise lone caregiving mothers or wives (Grant & Wenger, 1993; Litwak et al., 1994; Tausig et al., 1992). A lack of both additional female and male network members, therefore, may place those care-receivers at risk for poor care outcomes over the long-term.

Relationship Composition

Historically, greater normative expectations to provide care for people with disability also have been most closely associated with close kin social roles as opposed to those of non-kin (Bowling & Browne,1991; Campbell et al., 1999; Grant & Wenger, 1993; Walker et al., 1994). In addition, the embedded, long-term nature of most close kin relationships (Tijhuis et al., 1998) tends to foster a sense of social commitment (Phillipson, 1997; Tausig et al., 1992) or moral obligation to provide care (Ingersoll-Dayton & Antonucci, 1988) and makes it more likely that care is being reciprocated as repayment of support provide by an individual prior to the onset of disability (Ingersoll-Dayton & Antonucci, 1988).

Generally, social norms for providing help to most commonly are associated with the care of children or seniors but not adults (Litwak et al.,1994) which makes it even less likely that non-kin will be expected or feel obligated to participate in a care network (Grant & Wenger, 1993). However, there is evidence that friends and neighbors do contribute to or supplement kin care when needed, especially in the absence of close kin (Barrett & Lynch, 1999; Cranswick, 1999, Keating et al, 1999), although they may not sustain or maintain network participation if the care-recipient's health declines (Grant & Wenger, 1993; Klein Ikkink & vanTilburg, 1998; Stone & Rosenthal, 1996).

Because kin historically have had greater normative expectations for providing care, it is likely that most care networks will comprise higher proportions of kin than non-kin and, those that do, will provide greater hours of care (Fast et al., in review; Kelin-Ikkink & van Tilburg, 1998; Pruchno, Burant and Peters, 1997). Furthermore, normative expectations for the provision of specific

kinds of care tasks suggest that close kin will provide more personal care as well as more instrumental or household type tasks. For example, a recent study of seniors' networks found that those with a higher proportion of kin were more likely to provide help with home maintenance, grocery shopping, transportation and banking and bill paying (Fast et al., in review).

Traditionally, neighbors and friends are ascribed fewer expectations to provide care and expectations that tend to focus on certain stages of the life course or specific care tasks. Neighbors primarily are expected to provide limited emergency aid, surveillance and monitoring (Campbell, et al., 1999; Wenger, 1994) to older adults with disability or the parents of children with disability (Litwak et al., 1994). Expectations of friends primarily are to provide advice, companionship and emotional support (Campbell, et al., 1999; Litwak et al., 1994).

Greater emphasis placed on friend relationships by adolescents and young adults may make them more prominent in the care networks of younger rather than older adults with disability (Campbell et al., 1999; Litwak et al., 1994; Levitt et al., 1993). As well, it has been speculated that high rates of divorce and remarriage affecting kin relationships eventually may alter traditional expectations for caregiving and place greater expectations for care network membership on close friend relationships that may prove more robust over the long-term (Himes & Reidy, 2000).

In summary, care networks that do not have high proportions of close kin may not be able to provide large amounts of instrumental or personal care tasks if required. However, a varied relationship composition may allow care networks to provide a greater range of care tasks. Younger adult care-receivers may be more at risk for unmet care needs, especially instrumental care needs, than older adults because they are less likely to have developed a variety of long-term relationships or to have a spouse or children, but more likely to emphasize friend relationships with traditionally more limited expectations for long-term caregiving (Grant & Wenger, 1993; Litwak, 1994; Tausig et al., 1992).

Age Composition

The literature suggests tha age of care network members likely will correspond with the developmentil age of the care-receiver and the developmental stage of their famiy. For example, seniors are more likely to be present in the care networks of younger and older adult care-receivers. These would be grandparents in the former case and aging parents or older spouses in the latter. Overall, it has been suggested that middle-aged adults are the most prevalent care providers (Nolan e al., 1996; Keating et al., 1999). In terms of the population of interest to this sudy, middle-age parents likely figure prominently in the care networks of younger adults with disability and middle-age spouses likely are central in the networks of middle-age care receivers (Litwak et al., 1994).

Caregivers in different agegroups each face potential limitations or negative influences on the extentor duration of care network participation. For example, the participation of seniors in care networks is likely to be limited by their own eventual health deterioation, the participation of young individuals may be limited by immature physical sature or lack of motor skills, and the participation of middle-age adultsoften is limited by competing career and family demands (Grant & Wenger, 1993 Litwak et al., 1994). Regardless of competing demands, middle-age individualscould face high expectations for care network participation. Although not explictly evidenced in the literature, middle-age individuals likely possess greaterphysical, cognitive and financial resources to provide care and may be more likely to have developed a range of relationships over time with individuals to whon they feel obligated to provide care due to normative expectations or reciprocity.

Overall, the impact of agecomposition on the kinds and amount of care provided is inconclusive. There is some suggestion that healthy, unemployed seniors provide greater hours of care (Gallagher, 1994) and are more likely to help with transportation and grocery shopping but less likely to help with home maintenance than networks with predominantly middle-age adult members (Tennstedt, Crawford & McKinlay, 1993; Fast et al., in review). As noted above,

however, the ability of seniors to participate in care tasks may not last over the long-term.

Density

Density, or the amount of contact or familiarity between people in a group, is typical of long-term, socially embedded relationships such as close kin relationships (Bowling et al., 1991; Wenger, 1994). As previously speculated, if care networks are likely to comprise mostly kin, they are also likely to be densely-knit.

Densely-knit care networks may be able to provide more hours of care as density is thought to facilitate the coordination and mobilization of care resources (Bowling, Farqhar & Browne, 1991; Pescosolido, 2001; Tausig et al., 1992; Wenger, 1994). Furthermore, greater contact and communication between densely-knit care network members can facilitate the reciprocation of support from one member to another on behalf of the individual with the disability (referred to as generalized reciprocity) (Tijhuis et al, 1998). One study suggests that densely-knit networks provide higher levels of instrumental care tasks (Wenger, 1994) while care provided by more loosely-knit networks, comprising a variety of unrelated individuals, may be more sporadic, short-term or focused on non-instrumental type tasks such as providing emotional support (Phillipson, 1997; Wenger, 1994). Still, unlike densely-knit networks that are more likely to share a common knowledge and resource base, loosely-knit networks may be able to provide greater access to a more diverse range of care resources (Lubben & Gironda, 1996; Wenger, 1994).

Due to their longer lifespan and greater likelihood of being married with children, middle-age care-receivers likely possess greater numbers of long-term and close-kin relationships than younger adults with disability (Grant & Wenger, 1993; Litwak et al., 1994; Tausig et al., 1992). Thus, middle-age care-receivers also may tend to have more densely-knit care networks.

Proximity

Not only does geographic proximity facilitate density, reciprocal interaction over time and, therefore, potential for care network membership (Tijhuis et al.,

1998), it is also vitally important for the provision of many direct and instrumental kinds of care tasks by care networks. While emotional support, care management and monitoring tasks can be provided at a distance via telephone, mail or email, tasks such as housecleaning and personal care requires at least some care network members to be close by (Armstrong & Kits, 2001).

Care networks may enlist fewer proximate members if emotional support is the primary requirement. However, unavailability of proximate members when instrumental care tasks are required may leave some individuals with unmet care needs, prompt caregivers or care-receivers to move in order to facilitate the provision of care (Boaz & Hu, 1997; Cranswick, 1999) or result in a greater reliance on formal services (Phillipson, 1997). A recent study of seniors' care networks in fact found that close proximity or, especially, co-residence of care network members was most strongly associated with the probability that a care-recipient would receive help with every instrumental care task, including personal care, except transportation (Fast et al., in review).

Overall, care networks likely comprise greater proportions of proximate members that at least reside in the same community as the care receiver (Tausig et al., 1992). Younger adults with disability, especially those who require physical or personal care tasks, tend to live with at least one care network member and/or have a higher proportion of proximate care network members (Grant & Wenger, 1993). Close proximity can facilitate the amount of time spent providing instrumental care tasks that are frequently required or otherwise intense in nature. Thus, care networks with high proportions of proximate members are likely to provide more hours of care tasks, especially instrumental tasks, than those with few or no proximate members (Keating et al., 1999; Fast et al., in review).

Summary

It appears that normative expectations, history of reciprocity and long-term duration or embeddedness of relationships are important factors influencing the care network characteristics and outcomes of young and middle-aged adults with

disability. In addition, variation in care network characteristics also seems to be somewhat influenced by care-receiver health status, gender, co-residence and age. For the majority of young and middle-age individuals with disability, however, their care networks likely are small and densely-knit with high proportions of proximate, close kin and female family members providing the most care, tasks associated with female gender and, especially, more instrumental and personal care tasks.

Some Canadian data on young to middle-aged adults with disability show that their care networks do, in fact, comprise primarily family members (FPTM, 2000), most of whom are women, with primary caregiving roles falling to parents and especially to mothers (Grant & Wenger, 1993; Tausig et al., 1992). Typically, a minority of care network members are friends (FPTM, 2000;Tausig et al., 1992). Furthermore, many of these individuals with disability lack adequate support for their care needs. FPTM (2000) reveals that, in 1991, more than half of the one million individuals with disability aged 15 to 64 reported not receiving enough or any assistance with the every day activities for which they required help.

The idea that people with disability tend to have small and homogeneous networks with limited capacity contradicts policy assumptions that individuals with disability are able to rely on networks of social relationships that are able to provide a necessary amount and range of care tasks over a long-term. In order to update existing, limited information and examine policy assumptions, this study will test hypotheses derived from the literature regarding care network characteristics and their relationship to care outcomes, or the type and amount of care provided.

Hypotheses

1. Care networks will be small, densely-knit and comprise higher proportions of female, kin, middle-age, and geographically proximate members.
2. The provision of meal preparation, housecleaning, and banking will be associated with larger care networks and those comprising higher

proportions of women, kin and geographically proximate members. Provision of the remaining care tasks will be positively related to the proportion of kin in the network and all but transportation will be positively associated with having most network members living close-by. Male dominated networks are more likely to provide transportation and home maintenance but not grocery shopping while networks with mostly seniors are more likely to provide grocery shopping and transportation but not home maintenance.

3. Greater hours of care, overall, will be provided by larger, densely-knit networks and those comprising higher proportions of women, kin, seniors and geographically proximate members. Care networks with high proportions of women will provide more hours of housecleaning and personal care, and networks with greater numbers of kin and members living close-by are likely to provide greater amounts of instrumental type tasks.

CHAPTER THREE
METHODS

In the previous chapter, Symbolic Interaction theory and supporting literature were used to hypothesize the likely characteristics of care networks as well as the potential of those characteristics to influence care provided. In this chapter, methods are presented to test hypotheses using a nationally representative sample.

Source of Data

The 1996 Canadian General Social Survey (GSS), Cycle 11, was the source of data for this study of care networks. Each cycle of the GSS incorporates a different core content of questions in order to monitor social trends, living conditions and information relating to emerging and current policy issues affecting the well–being of Canadians. The focus of the 1996 GSS, 'social and community support', was relevant for this project as its focus was on the nature of help received and provided by family members and friends as well as the extent of met or unmet needs for help (Statistics Canada, 1998).

Between February and December 1996, random digit dialing was used to collect data from a representative sample of all non-institutionalized Canadians aged 15 years or older, living in private households in all provinces. There were 12,756 respondents in the sample with a response rate of 85.3%. Data were collected regarding the assistance that each respondent gave or received in the past year due to a long-term health or physical limitation.

Sample

The sample of interest to this study was 18 to 64 year olds who reported that they had received help with at least one care task in the past year from a family member, friend or neighbor because of their own long-term health or physical limitation. There were 187 (87 male and 100 female) people who received this kind of assistance.

Operational Definition of Variables

Operational definitions of variables used in this study primarily were derived from the review of literature but also reflect the form and content of the questions used in the 1996 GSS to gather data on family and friend care.

Care recipients were individuals who responded that they had received one or more care tasks in the past 12 months because of their long-term health or physical limitation(s) (a chronic or permanent condition and that is expected to last more than six months) (Keating et al., 1999).

Caregivers were family members, friends, neighbors or co-workers named by respondents as having provided them with one or more care tasks in the past 12 months because of the respondents' long-term health limitation(s).

Care task(s) referred to categories of assistance provided to respondents including: meal preparation or cleanup; shopping or transportation; housekeeping (including sewing and laundry), home maintenance, repair or yard-work; banking or bill paying; personal care (such as help with bathing, dressing, toileting, hair, nail or dental care); child care; emotional support; monitoring or 'checking-up' on the care recipient by visiting or telephoning.

Care networks included all family members, friends, neighbors or co-workers who, respondents reported, helped them with one or more care tasks in the past year.

Characteristics of care networks that were of interest to this study included size, composition, proximity and density. Unfortunately, only size, composition and proximity could be operationalized for inclusion in the analyses. Due to limitations of the data set, it was not possible to measure care network density or the degree of contact among members.

Care network size was a count of all family members, friends, neighbors or co-workers who provided one or more care tasks to a respondent in the past 12 months. Also due to limitations of the 1996 GSS data set, it was only possible to ascertain the number but not the gender, relationship or proximity of care network members who provided emotional support and checking-up only.

As a result, respondents whose care networks were a source of emotional support or monitoring only were excluded from this study.

Care network composition was measured in three ways. Gender composition was measured as the proportion of women in the care network. Relationship composition was operationalized as the proportion of kin in the network. Kin included parents, siblings, children, all categories of extended kin, in-laws and same-sex or common-law partners while non-kin members are friends, neighbors or co-workers. Age composition was measured as the proportion of the network less than 24 years of age, age 25 to 64 and age 65 and over.

Care network proximity was operationalized as the proportion of the network that lived close by, at mid-range or far away. Close by network members lived in the same household, building, neighborhood or community as the care-recipient. Mid-range members did not live in the same community but lived less than half a day away by car from the care recipient. Far away members lived more than a half day's commute. The category of mid-range care network members was left out of the regression analyses because it tended to correlate with the other proximity variables.

Analyses

Chapter 2 attempted to move beyond a traditional focus on pairs of caregivers and care-receivers and develop hypotheses about the characteristics of groups or networks providing care. The unit of analysis for this research project also reflected a focus on care networks rather than care dyads.

Due to their differing likelihood of having a spouse or child as members of their care network, the review of literature suggested that care network characteristics likely would vary between young adult and middle-age adult respondents. Thus, respondent age group was controlled for along with other care-recipient traits that the literature suggested would correlate with network characteristics to influence the type and amount of care provided. Additional control variables included care-recipient co-residence, gender and health status.

Unfortunately, though previous research had suggested that co-residence of respondents with a care network member would be a strong predictor of care outcomes (Fast et al., in review), information regarding co-residency was suppressed in the dataset used for this analysis. Because many co-resident respondents would be living with a spouse, marital status was used as a proxy control for co-residency. However, it was acknowledged that marital status would not capture those situations in which care-recipients were co-residing with a parent or other network member.

Respondent gender was controlled for due to speculation by previous research that male respondents tend not recognise certain tasks as being care. Rather, tasks such as house cleaning or meal preparation may be underreported as care tasks if a respondent tends to associate them with the non-caregiving or gender roles, for example, of their wife or mother and, especially, if the tasks also were provided prior to the onset of the respondent's health limitations (Keating et al., 1999).

The review of literature also cited evidence that care-receivers in the poorest health would be most likely to have small networks (Litwin, 1997A) implying they would receive less care than those with large networks. Therefore, health status was included as a control in the analysis. However, a review of initial results suggested there to be a non-linear relationship between the two variables. Thus, a quadratic function also was used to test for a possible curvilinear relationship between network size and health status.

The measure of health status used in the analyses was a self-report health survey question incorporated in the 1996 GSS asking respondents to describe their state of health, as compared to other people their age, on a 5-point scale ranging from excellent to poor (Statistics Canada, 1998). While self-reported health is an easy and efficient survey tool, it also has been shown to be strongly and reliably correlated with more objective measures of health status, especially functional health status, as well as with specific health behaviors, certain illnesses, morbidity and changes in health for Canadian, senior and

younger adult populations as well (Cott, Gignac & Bailey, 1999; Manor, Mathews & Power, 2001; Ratner, Johnson & Jeffery, 1998).

Hypothesis 1: Care networks will be small, densely-knit and comprise higher proportions of female, kin, middle-age, and geographically proximate members.

Descriptive analyses were used to test the likelihood that care networks will possess the characteristics postulated by the first hypothesis. Descriptive analyses were conducted for the entire population sample as well as for both age group sub-samples The size of care networks was measured in terms of the frequency of networks with sizes of 1, 2, 3 to 4 or greater. Next, the number and proportion of care networks possessing other network characteristics, described above, were examined. Frequencies and sample proportions were ascertained to describe networks comprising entirely kin or non-kin, men or women, young, middle-age or older network members, close-by, midrange or far away members. Networks comprising mixed genders, relationships, ages or proximity also were distinguished.

Hypothesis 2: The provision of meal preparation, housecleaning, and banking will be associated with larger care networks and those comprising higher proportions of women, kin and geographically proximate members. Provision of the remaining care tasks will be positively related to the proportion of kin in the network and all but transportation will be positively associated with having most network members living close-by. Male dominated networks are more likely to provide transportation and home maintenance but not grocery shopping while networks with mostly seniors are more likely to provide grocery shopping and transportation but not home maintenance.

Logistic regression was used to examine whether individual network characteristics, described above, predicted whether different types of care tasks were provided by the care network. The dependent variables were coded as 1 if the respondent received help with the task from their care network and 0 if they did not. Tasks included were meal preparation, house cleaning, house maintenance, grocery shopping, transportation, banking and bill paying and

personal care. Childcare was not included as a task category as too few in the sample received help with this task.

Hypothesis 3: Greater hours of care, overall, will be provided by larger, densely-knit networks and those comprising higher proportions of women, kin, seniors and geographically proximate members. Care networks with high proportions of women will provide more hours of housecleaning and personal care, and networks with greater numbers of kin and members living close-by are likely to provide greater amounts of instrumental type tasks.

Ordinary Least Squares (OLS) regression was used to examine whether individual network characteristics predicted the total amount of care provided. The dependent variables for this analysis were the total amount of time (measured in hours/week) spent by all network members providing all care tasks as well as individual care tasks. The individual tasks were the same as those included in the logistic regression analyses.

All analyses were weighted in order to compensate for the over and under-representation of sub-groups in the 1996 GSS and so that results would be representative of the general Canadian population (Statistics Canada, 1998). The weighted sub-sample for the 187 GSS care-recipients between ages 18 and 64 represents 536,161 individuals in the general population. Furthermore, Statistics Canada (1998) guidelines that suggest cell sizes with $n < 15$ not be reported in order to respect the confidentiality of respondent data and to promote the reliability of findings were adhered to.

CHAPTER 4
RESULTS

This chapter presents the results of statistical analyses conducted to test the hypotheses about care network characteristics that were derived and posed in Chapter 2. Analyses were conducted for the entire sample of 18 to 64 year olds with long-term health limitations and included controls for respondent age, co-residence, gender and health status. The most commonly received tasks were help with meal preparation and house cleaning followed by help with grocery shopping, home maintenance, transportation and banking and bill paying. Only one third of the sample received personal care despite the fact that more than double that number reported being in fair to poor health.

Hypothesis 1: Care Network Characteristics

The first hypothesis was that care networks would be small, densely-knit and comprise higher proportions of female, kin, middle-age and geographically proximate members.

The results showed that care networks across the whole sample were small (see Table 2) with a mean size of 1.6. Sixty-two percent of the sample had care networks comprising only one caregiver while 23.5% had networks comprising two caregivers.

Also supporting hypothesis 1, care networks predominantly comprised only women (45.6%), kin (81.3%), members aged 25 to 64 (68.0%), and those living close-by the care-receiver or in the same household, building, neighborhood or community (76.9%). No care networks had all members living more than a half-day drive away.

Table 1: Sample Characteristics			
Descriptor		**Whole Sample**	
N=		187	
		#	%
Respondent (Care Receiver) Characteristics:			
Gender:	male	87	46.4
	female	100	53.6
Marital Status:	married	132	71.6
	not married	52	28.4
Health Status: (self-report)	very good to excellent	21	12.0
	good	49	28.3
	fair to poor	105	59.6
Care Tasks Received:			
Long Term Duration of Care[1]		153	81.9
Receipt of:	child care	-	-
	meal prep	120	64.1
	house clean	121	64.6
	home maint.	88	47.0
	grocery shop	99	53.0
	transport	90	48.0
	bank & bill pay	66	35.5
	personal care	56	29.9
A dash (" – ") represents cell sizes </= 14			

[1] Receipt of any care task for two years or longer

Table 2: Descriptive Analyses Receivers of Care Tasks from a Care Network		
Descriptor	**Whole Sample**	
N=	187	
	#	%
Care Network Characteristics:		
Size: 1	116	62.0
2	44	23.5
3 - 4	19	10.5
5-6	-	-
Relationship Composition:		
kin only	152	81.3
non-kin only	16	8.8
mix kin/non-kin	19	9.9
Gender Composition:		
male only	45	24.3
female only	85	45.6
mix male/fem.	57	30.1
Age Composition:		
all age 0-24	-	-
all age 25-64	127	68.0
all age 65+	-	-
mix ages	43	23.3
Proximity:		
all living close[2]	144	76.9
all living near[3]	15	8.1
all living far[4]	N/A	N/A
mix proximity	28	15.0
A dash (" – ") represents cell sizes </= 14		

[2] Living in the same house, building, neighbourhood or community
[3] Living in the same area, less than half a day away
[4] Living more than half a day away

Hypothesis 2: Predictors of Type of Care Received

The second hypothesis was that the provision of meal preparation, housecleaning, and banking would be associated with larger care networks and those comprising higher proportions of women, kin and geographically proximate members. Provision of the remaining care tasks would be positively related to the proportion of kin in the network and all but transportation would be positively associated with having most network members living close-by. Male dominated networks would be more likely to provide transportation and home maintenance but not grocery shopping, while networks with mostly seniors would be more likely to provide grocery shopping and transportation but not home maintenance.

The results show that care network size was significantly associated with provision of every care task except personal care (see Table 3). For every additional care network member, respondents were almost twice as likely to be provided help with meal preparation, housecleaning, home maintenance and banking or bill paying. The same individuals were 2.4 times as likely to be provided help with transportation and 1.6 times more likely to be provided help with grocery shopping.

Neither care network gender composition nor relationship composition were strongly related to the kinds of care tasks provided. The only significant finding was that individuals who had only female network members were less likely to be provided help with home maintenance.

The hypothesized relationship between proximity and type of task received was partially supported. The findings showed that respondents with all care network members living close-by were 5 times more likely to have help making meals or to have meals provided for them. Proximity of care network members was not related to provision of housecleaning or personal care.

Table 3: Logistic Regression
Receipt of Care Task (yes/no) by Care Network Characteristic[5]

Character-istic	Meal Prep.	House Clean.	Home Main.	Groc. Shop	Trans-Port.	Ban & Bill	Pers. Care
N =	178	178	178	178	178	178	178
	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald Statistic)*	Odds Ratio *(Wald* Statistic)
Care Network Characteristics: Independent Variables							
Size	2.049** (7.709)	1.973** (7.023)	2.177** (8.623)	1.611* (4.324)	2.402** (10.074)	1.789** (7.001)	1.203 (1.029)
Proportion Kin	2.265 (1.697)	1.082 (0.017)	0.361 (2.128)	1.446 (0.323)	3.723 (3.665)	3.276 (2.831)	1.190 (0.061)
Proportion Age 25-64	1.006 (0.520)	1.001 (0.010)	0.985 (3.181)	1.036** (9.863)	1.064*** (16.083)	1.036** (7.614)	0.997 (0.155)
Proportion Age 65+	1.022 (3.495)	1.025* (3.802)	0.988 (1.080)	1.039** (8.870)	1.063*** (14.146)	1.034* (5.545)	0.987 (1.128)
Proportion Female	1.124 (0.051)	1.092 (0.031)	0.111*** (14.668)	0.462 (2.334)	0.452 (2.342)	0.506 (1.702)	1.665 (0.823)
Proportion Close[6]	4.839** (6.535)	1.764 (0.937)	1.303 (0.138)	1.192 (0.090)	2.077 (1.387)	3.144 (3.060)	0.780 (0.162)
Proportion Far[7]	1.379 (0.007)	1.726 (0.017)	19.461 (0.557)	0.000 (1.429)	0.000 (1.955)	0.000 (0.176)	1.513 (0.010)
Respondent Characteristics: Control Variables							
Gender[8]	0.975 (0.003)	0.899 (0.063)	2.595* (3.795)	1.285 (0.345)	1.549 (0.963)	1.416 (0.640)	1.450 (0.714)
Marital Status[9]	1.726 (1.255)	1.744 (1.406)	7.192*** (12.075)	0.475 (2.362)	0.250** (6.937)	0.570 (1.281)	1.585 (0.799)
Health Status[10]	16.355* (5.424)	4.125 (1.979)	4.431 (2.255)	0.941 (0.004)	0.491 (0.506)	1.611 (0.206)	1.336 (0.063)
Health Status Squared	0.714* (4.166)	0.869 (0.984)	0.814 (2.125)	1.077 (0.317)	1.129 (0.760)	0.974 (0.034)	0.986 (0.008)
Age Group[11]	0.446 (2.534)	0.709 (0.520)	0.898 (0.048)	1.774 (1.494)	2.030 (2.129)	1.055 (0.012)	1.075 (0.019)
Model Characteristics:							
Constant	0.000*** (11.709)	0.011* (4.693)	0.088 (1.361)	0.008* (4.778)	0.001** (7.864)	0.004** (8.526)	0.063 (1.435)
2 Log Likelihood	189.549***	199.049**	184.072***	203.473***	193.912***	197.420**	189.994
Nagelkerke R^2	0.276	0.212	0.369	0.258	0.317	0.207	0.092

[5] Significance level: *** = p < O.001, ** = p < 0.01, * = p < 0.05
[6] Living in the same house, building, neighbourhood or community
[7] Living more than half a day away
[8] Gender: 0= female, 1 = male
[9] Marital Status: 0 = not married, 1 = married or common law
[10] Self Reported Health Status: 1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor
[11] Age Group: 0 = 18 to 34 years, 1 = 35-64 years

In terms of network age composition, for every 10% increase in the proportion of network members between 25 and 64 years of age, respondents were between 10% and 11% more likely to be provided help with grocery shopping, transportation and banking or bill paying. An increase in the proportion of seniors also slightly improved the odds that a care network would provide help with housecleaning.

Associations between respondent characteristics and provision of care tasks were observed as well. Results show that male respondents were 2.5 times more likely than female respondents to be provided help with home maintenance while married care-receivers were over 7 times more likely than single care-receivers to be provided help with this task but less likely to be provided help with transportation.

Respondent health status was another characteristic that was significantly related to the receipt of help with meal preparation. With every one-unit decrease in self-reported health status, respondents initially were 16 times more likely to receive help with meal preparation. However, when self-reported health status was tested further using a quadratic function (the square of its value), results showed a curvilinear relationship between declining health and provision of help with meal preparation. That is, while respondents in declining health initially were provided additional help with meal preparation, those in poorest health were provided less.

Overall, all network characteristics except kin composition and proportion of members living at a distance contributed reasonably well to the explanatory power of logistic regression models predicting the probability of being provided different kinds of care tasks. Models were able to predict the provision of all care tasks except personal care. The explained variance of the predictive models, indicated by Nagelkerke R^2 values, ranged from a low of 20.7% for the banking and bill paying model to a high of 36.9% for the home maintenance model.

Hypothesis 3: Predictors of Amount of Care Received

The third hypothesis stated that more hours of care overall would be provided by larger, densely-knit networks and those comprising higher proportions of women, kin, seniors and geographically proximate members. Care networks with high proportions of women were expected to provide more hours of housecleaning and personal care, and networks with greater numbers of kin and members living close-by were expected to be more likely to provide greater amounts of instrumental type tasks.

Care network size was a significant predictor of the amount of care provided (see Table 4). On average, with every additional network member, respondents were provided an additional 4½ hours per week of help. As well, a one unit increase in network size was associated with the provision of more than a half-hour per week of additional help with grocery shopping and transportation and more than an hour and a half more help with personal care.

Proximity of care network members also appeared to be related to amount of care provided. Networks with all proximate members provided up to 9.5 more hours of total care per week, 4.5 more hours of help with meal preparation and 1.5 more hours of help with transportation than those with no proximate members.

Hypotheses regarding the relationships between other network characteristics and amount of care provided were not well supported. Relationship composition did not appear to be associated with amount of care provided in any task category. Gender composition was associated only with amount of home maintenance provided with results showing that all female care networks provide fewer hours per week of that care task than all male networks.

Table 4: Linear Regression
Amount (hours/week) of Care Task by Care Network Characteristic[12]

Character-istic	All Care	Meal Prep.	House Clean.	Home Main.	Groc. Shop	Trans-Port.	Bank & Bill	Pers. Care
N =	175	170	171	171	174	170	174	171
	Beta[13] *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*	Beta *(t-stat)*
Care Network Characteristics: Independent Variables								
Size	4.441*** (3.564)	1.065 (1.569)	0.549 (1.783)	-0.0259 (-0.302)	0.623*** (5.887)	0.663*** (3.611)	0.022 (1.296)	1.623** (3.011)
Proportion Kin	2.270 (0.545)	0.393 (0.176)	1.099 (1.074)	0.284 (0.975)	0.247 (0.690)	0.674 (1.092)	0.076 (1.335)	-0.394 (-0.212)
Proportion age 25-64	0.034 (0.661)	-0.014 (-0.490)	-0.007 (-0.582)	0.002 (0.601)	0.017*** (3.771)	0.024** (3.119)	0.001 (0.733)	0.014 (0.639)
Proportion age 65+	0.098 (1.464)	0.014 (0.373)	0.019 (1.174)	0.005 (1.190)	0.018** (3.101)	0.017 (1.688)	0.001 (0.187)	0.032 (1.117)
Proportion Female	-1.029 (-0.302)	0.471 (0.256)	-1.398 (-1.657)	-0.739** (-3.151)	-0.409 (-1.411)	0.639 (1.264)	-0.026 (-0.566)	0.242 (0.164)
Proportion Close[14]	9.463* (2.423)	4.581* (2.186)	-0.328 (-0.340)	0.362 (1.360)	0.527 (1.581)	1.506** (2.612)	0.028 (0.523)	2.943 (1.744)
Proportion Far[15]	9.162 (0.322)	13.196 (0.866)	4.104 (0.587)	0.682 (0.352)	-2.571 (-1.065)	-3.851 (-0.926)	-0.286 (-0.740)	-3.633 (-0.296)
Respondent Characteristics: Control Variables								
Gender[16]	4.151 (1.475)	2.986* (1.968)	0.496 (0.713)	0.040 (0.210)	0.180 (0.751)	-0.879* (-2.118)	-0.009 (-0.233)	0.837 (0.851)
Marital Status[17]	4.066 (1.306)	2.045 (1.224)	1.095 (1.429)	0.451* (2.107)	0.191 (0.723)	-0.835 (-1.823)	-0.028 (-0.664)	0.309 (0.285)
Health Status[18]	14.545* (2.315)	5.188 (1.525)	2.440 (1.567)	0.898* (2.078)	0.447 (0.836)	0.407 (0.442)	-0.009 (-0.116)	5.082 (1.869)
Health Status Squared	-1.892* (-2.130)	-0.580 (-1.202)	-0.275 (-1.242)	-0.131* (-2.132)	-0.047 (-0.619)	-0.093 (-0.714)	0.004 (0.314)	-0.756 (-1.962)
Age Group[19]	-7.333* (-2.130)	-3.317 (-1.935)	-1.590* (-2.021)	0.005 (0.023)	0.206 (0.759)	-0.091 (-0.194)	0.012 (0.292)	-0.103 (-0.074)
Model Characteristics:								
Constant	-31.369* (-2.419)	-9.682 (-1.398)	-2.678 (-0.839)	-1.452 (-1.629)	-3.271** (-2.960)	-3.313 (-1.739)	-0.057 (-0.324)	-12.596* (-2.248)
F – statistic	3.420***	2.611**	1.999*	2.442**	5.052***	2.039*	0.630	1.498
R^2	0.203	0.167	0.132	0.157	0.274	0.136	0.045	0.102

[12] Significance level: *** = p < O.001, ** = p < 0.01, * = p < 0.05
[13] un-standardized coefficients
[14] Living in the same house, building, neighbourhood or community
[15] Living more than half a day away
[16] Gender: 0= female, 1 = male
[17] Marital Status: 0 = not married, 1 = married or common law
[18] Self Reported Health Status: 1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor
[19] Age Group: 0 = 18 to 34 years, 1 = 35-64 years

Respondent characteristics also were associated with the amount of care that was provided to them. Younger respondents (aged18 to34) were provided 7 hours per week less help, overall, than adults aged 35 to 64 and 1.5 fewer hours of help with housecleaning. Male care receivers were provided almost three more hours per week of meal preparation and slightly less than an hour of additional help with transportation than women. Married care receivers received an additional half-hour of help with home maintenance over those who were single.

Respondents' health status also was related to hours of care they were provided. With every one-unit decrease in health status, respondents initially were provided more than 14 hours additional help. Results showed, however, that at some point the trend reversed so that respondents in poorest health actually were provided fewer hours of care. The same pattern was observed with hours of home maintenance provided. As health status initially declined, respondents experienced close to one hour of additional help with home maintenance but those with the poorest health status were provided less.

Similar to the logistic regression, all network characteristics except relationship composition and proportion living at a distance were significant predictors of the dependent variables. Results of the linear regression showed that network characteristics predicted the total hours of care provided as well as the amount of help provided in each task category except house cleaning, baking and bill paying and personal care. The full model explained 20.3% of the variance in total amount of care provided while models for individual tasks predicted 13.2 to 27.4% of the variance in hours provided of specific care tasks. Neither the model for receipt of help with banking and bill paying nor for help received with personal care were significant.

Data Limitations

A key limitation impacting the results of this study was reliance on a secondary data file that restricted analyses of variables to those included in the original study. For example, the literature suggested that care network density and respondent co-residence likely would contribute to the explanatory power of the regression models but neither variable could be included due to limitations of the data set. In addition, the sample size (n = 187) was extremely small, leading to the suppression of some descriptive statistics, possibly limiting the expected results of the regression analysis and, thus, limiting the discussion.

CHAPTER FIVE
DISCUSSION

The purpose of this research project was to move beyond the dyadic approach of previous caregiving research and determine the characteristics of networks of family, friends and neighbors providing care in the community to young and middle-aged Canadian adults with disability. Due to the unyielding and growing reliance on these care networks resulting from current sociopolitical and demographic changes, this study also sought to better understand the capacity of care networks and their potential to provide different kinds and amounts of care over the long term. This chapter will discuss findings from the study in relation to the conceptual framework and literature previously reviewed. Implications of the study for future research and policy also will be discussed.

Care Network Characteristics

Symbolic Interaction theory provided the conceptual rationale for a focus on care networks, rather than care dyads, by encouraging the examination of shared meanings that commonly are ascribed social roles and that foster expectations for care from a variety of sources. Results of the study, demonstrating that many adults with disability do have groups of individuals providing them with a variety of care tasks, further justify the use of networks as the unit of analysis in caregiving research.

However, contrary to current health and continuing care policy assumptions that large networks of family and friends are readily available to provide care (Home Care Development Canada, 1999), this study revealed networks of persons caring for Canadian adults with disability to be extremely small. In addition, the characteristics of care networks tended to mimic characteristics of the average caregiver found in previous research (Keating et al., 1999). In other words, care networks primarily were small and made up of female, kin and middle-aged individuals living close-by.

These results were expected, based on the review of literature using a Symbolic Interaction framework. However, Symbolic Interaction theory primarily focuses on the meanings and motivations derived from the social interaction

between individuals. An examination of meanings shared or negotiated among groups or networks of individuals may have helped to predict the substantial variability in network characteristics that this study found as well. Results showed, for example, that substantial numbers of men, non-kin, young people and seniors also were contributing to care networks despite low normative expectations for their involvement.

Care Network Outcomes

By providing a conceptual framework for identifying the social roles commonly ascribed expectations for care and, thus, potential sources of caregiving behavior, Symbolic Interaction theory also was used to derive hypotheses regarding the important and likely characteristics and outcomes of networks providing care for young and middle-aged adults with disability. Key concepts encompassed by Symbolic Interaction theory that helped to formulate the hypotheses for testing (Keating et al., in press), including social capital, embeddedness, reciprocity and normative expectations, also help to elucidate some of the unexpected findings resulting from the analysis.

Outcomes related to Network Size

Using a Symbolic Interaction framework, the review of literature suggested that negative influences affecting the ability of adults with disability to build up and maintain social capital and, therefore, the potential for care network membership (Crichton & Jongbloed, 1996; Litwak et al., 1994), would result in predominantly small network sizes that would limit the amount and variety of care provided (Grant & Wenger, 1993; Pescosolido, 2001). However, possible relationships between care network size and specific care tasks were not predicted.

Interestingly, network size was associated with the receipt of some tasks, and the amount provided of other tasks, but not both together. So, for example, larger network size predicted the likelihood of actually receiving meal preparation, house cleaning and home maintenance but only predicted how many hours of care would be received for the remaining care tasks, including grocery shopping, transportation and personal care. When all care tasks were

considered together respondents received up to 4 more hours per week of additional help, overall, for every additional member in their network.

Unfortunately, it is unlikely that all respondents had adequate network membership to meet all of their care needs. It is reasonable to assume that those in poorest health would require larger networks that, research shows, are able to provide a greater variety and amount of care (Pescosolido, 2001; Fast et al., in review). However, poor health also impacts ability to maintain social interaction or reciprocity and therefore acts as a disincentive to potential care network membership (Tijhuis et al., 1998; Walker et al., 1994). As the results of the study show, while close to 60% of the sample reported being in fair to poor health, only 15% of the sample had care networks of more than two members. Furthermore, although it appeared that the amount of help provided by care networks initially did increase by as much as 14 hours/week when health status began to decline, the trend reversed at some point so that those reporting the poorest health actually received the least care. This result is consistent with the findings of at least one other study which suggested that those in the poorest health probably had the smallest networks (Litwin, 1997A).

Longitudinal research is needed to fully understand the relationships between network size, health status and care outcomes. Overall, however, the data suggest that care networks likely will exceed their capacity to provide care, or may even collapse, in the face of escalating care needs over the long-term. From the Symbolic Interaction perspective, escalating care needs likely would result in growing perceptions of caregiver burden and role strain that would help to further explain reductions in care network size and amount of care provided found in this study (Allen & Mor, 1997; Kramer & Lambert, 1999).

Outcomes Related to Network Composition

The review of literature, based on Symbolic Interaction theory, did suggest that the implications of small network size for poor care resources might be moderated by higher proportions of women and kin in the network, both with greater normative expectations for providing more kinds and amounts of care (Tausig et al., 1992; Campbell et al., 1999). Unexpectedly, however, results

showed few significant relationships between either gender or relationship composition and care outcomes other than all-female networks being both less likely to provide home maintenance and to provide fewer hours of the task than all male networks.

Similar findings regarding the association between female gender and probability of receiving home maintenance were found in a recent study of seniors' networks (Fast et al., in review). In addition, the study of seniors' care networks found some of the expected relationships between gender, relationship composition and care outcomes that this study did not. For example, all female networks were more likely than all male networks to provide seniors with care tasks typically associated with female gender, such as meal preparation or housecleaning, while all male or all non-kin networks provided seniors with the fewest hours of care (Fast et al., in review).

One possible explanation for the lack of additional expected associations between female gender composition and care outcomes in this study is that women may have been under-represented in the dataset. For example, from a Symbolic Interaction perspective, this might happen if the network contributions of women were not recognized as being care because the tasks provided, such as house cleaning or meal preparation, overlapped with normative expectations for everyday activities already associated with female gendered social roles irrespective of the health status of the recipient(s) (Keating et al., 1999; Kramer & Lambert, 1999).

Based on Symbolic Interaction theory, social roles and related normative expectations also can change over time or in different contexts, offering an alternative explanation for the lack of significant findings related relationship composition (LaRossa & Reitzes, 1993). The review of literature had cited speculation, and some evidence, that rising rates of divorce, remarriage and female workforce participation in recent generations are shifting normative expectations for care away from a traditional emphasis on kin and women to a greater involvement of non-kin and men (Armstrong & Kits, 2001; Himes & Reidy, 2000). Therefore, greater participation of non-traditional caregivers in the

networks of a younger cohort of care-receivers might have reduced or nullified the expected effects of female or kin composition on care outcomes.

However, generational effects on relationship composition are not evident when comparing the results of this study with those found for seniors' care networks. The recent study by Fast et al. (in review) actually showed seniors to have even higher proportions of all male and all non-kin networks than adults with disability even though networks across both studies were similar in size and age composition.

The review of literature suggested that middle-aged adults would comprise the largest proportion of care networks for adults with disability because they would be more likely than younger individuals or seniors to have developed as well as maintained long-term embedded or relationships, with expectations for care to be reciprocated when needed (Nolan et al., 1996). Further, normative expectations for caregiving would tend to peak in middle-age because physical ability, financial and other necessary resources for providing care likely would be optimal at that point in the lifespan (Litwak et al., 1994). Not surprisingly, then, this study found that two thirds of the care networks of adults with disability to entirely comprise of individuals aged 25 to 64.

However, a 10% increases in both the proportion of the network aged 25 to 64 and the proportion over 65 effected only moderate increases in the probability that tasks such as grocery shopping and transportation would be provided. Interestingly, the study of seniors' networks found the provision of these same tasks to be strongly but negatively influenced by the proportion of the network under age 64, or under age 44 (Fast et al., in review). Differences between studies in the strength of associations between age composition variables and the probability of receiving various tasks likely is a result of differences in sample size, while differences in the direction of the association suggest that another influence is at play. From a Symbolic Interaction perspective, it could be that care-receivers hold different normative expectations for help from same age, versus younger or older, care network members.

Outcomes Related to Network Proximity

Hypotheses related to proximity of care network members also were supported by the regression analyses. Because close proximity can facilitate direct social interaction and reciprocity, and therefore the potential for care network membership (Tijhuis et al., 1998), it is not surprising that this study found the majority of care networks to comprise members all living close-by the care receiver. After network size, close proximity was the next strongest predictor of the total amount of care provided to adults with disability. However, the operationalization of proximity variables in this study may limit ability to accurately interpret findings regarding the influence of close proximity on care outcomes.

In this study, close proximity was defined as living in the same household, building, neighborhood or community as the care-receiver. Fast et al. (in review) were able to isolate the proportion of the care network co-residing with senior care-recipients and found that co-residence was, in fact, the aspect of close proximity that most strongly predicted the provision of both the total amount and a range of care tasks. It is possible that a similar association between co-residence and care outcomes exists for adults with disability who, research suggests, are likely to co-reside care network members (FPTM, 2000; Grant & Wenger, 1993). However, from a Symbolic interaction perspective, the type and nature of typical co-resident relationships, such as embeddedness or normative expectations commonly associated with close kin (Klein Ikkink & van Tilburg, 1998; Tijhuis et al., 1998), likely would factor in any ability of co-residence to predict care outcomes.

Respondent marital status was used as proxy for co-residence status. Results showed that respondents who were married were much more likely to be provided help, as well as somewhat more help, with home maintenance. Arguably, this finding might reflect the greater probability of married respondents owning their own home and re-emphasize the concern, expressed in the methods chapter, that marital status would not be an adequate proxy for co-residence because it fails to capture those situations in which a respondent was living with their parent or someone else.

Considerations for Future Research

Hypotheses regarding care network characteristics and outcomes were, for the most part, well supported by the results of this study. However, based on the review of literature some expected findings require clarification and further testing while other unexpected findings, and their possible relationships to data limitations, also suggest the need for additional and, especially, longitudinal research.

For example, the small size of networks caring for adults with disability was not unexpected and the finding is similar to network sizes found in other studies of adults with mental illness (Tausig et al., 1992) and seniors (Fast et al., in review). However, the literature suggests that small network sizes and the strong influence of close proximity on care outcomes both may be, in part, a function of the types of care tasks included in the analysis. Larger network sizes, similar to those found in a study by Tennstedt et al. (1989), and higher proportions of distant care network members may have resulted if it had been possible to also include in the analyses individuals who provided non-instrumental or other care tasks that are possible to provide from a distance. This would include tasks such as emotional support, monitoring or care-management (Armstrong and Kits, 2001; Fast et al., in review). As normative expectations for the provision of those tasks often are associated with friend and neighbor social roles, including those tasks likely would yield greater involvement of non-kin in the findings of future research on care networks (Campbell et al., 1999: Litwak et al., 1994).

Further research also is needed to clarify whether, or how, co-residence shares in the ability of close proximity to predict care outcomes and, if so, whether the explanatory power of co-residence might be shared with aspects of relationship composition such as proportion of close kin. However, co-residence may not prove to be a significant predictor of care outcomes for adults with disability, for example, if the emphasis on 'independent living' for this age group effects weaker associations between respondent co-residence and care

outcomes than were found in the study of seniors' networks (Crichton & Jongbloed, 1998; Fast et al., in review).

Overall, the differences found between this study and the study of seniors' networks in the number and/or strength of expected associations, especially between network composition and care outcomes, suggests that the latter study benefited from having a larger sample size. Although the same GSS database was used for both studies the database included an over-sample of seniors, in order that separate analysis could be done for that group, but a much smaller sample of adult respondents with long-term health limitations (Statistics Canada, 1998). The fact that this study found significant results, despite having a small sample, makes the findings even more noteworthy. Still, further testing with a larger sample is recommended in order to confirm or refute the findings of this study.

Including a measure of care network density, or the amount of contact or familiarity between network members, also is recommended for future research. Although evidence was lacking in this study, the literature had suggested that younger cohorts of care-receivers might be experiencing changing expectations of traditional caregivers (Campbell et al., 1999; Himes & Reidy, 2000; Litwak et al., 1994; Levitt et al., 1993). Therefore, network density, which is a reflection of the stability of long-term relationships and their ability to mobilize and provide care regardless of gender or relationship, might be an additional, or even a more accurate, predictor of care outcomes in the absence of strong and expected traditional associations with female or kin relationships (Bowlling & Browne, 1991; Fast et al., in review; Israe & Antonucci, 1987).

Finally, future longitudinal research also is needed to clarify the relationships between care network size, health and care outcome variables. The results of this study show that those in moderate or poor health have small networks and receive few hours of care. The results further suggest, but do not confirm, that declining health initially is associated with growth in network size and the amount of care provided until the capacity networks to continue to provide care is exceeded. While poor health limits ability to build up social

capital, care potential and, thus larger network sizes to begin with, the curvilinear pattern observed between care network size and declining health status is not well understood.

Overall, however, the predominance of generally small network sizes, and the idea that they will become smaller with continuing declines in health status, raises concern for the sustainability of care networks over the long-term as both adult care-receivers and their care network members age. As care-receivers age they are likely to experience additional declines in health status because they are more susceptible to developing additional health problems, compounded by health related effects of the normal aging process, than those who do not have a pre-existing condition (Ostir, Carlson, Black, Rudkin, Goodwin & Markides, 1999). At the same time, the size and capacity of a care-receiver's network also is likely to fluctuate or decline over time as care network members face their own age-related health deterioration or changes in demands, related to life cycle transitions, that compete with their ability to continue to provide care (Grant & Wenger, 1993; Litwak et al., 1994; Myles, 1993).

Thus, it is likely that adults with disability, who already experience small network sizes and limited capacity, will face even further reductions over time as their need for care increases. So, while this study found care networks similar in size and composition to seniors networks (Fast et al, in review), adults with disability likely will find themselves experiencing even smaller, more restricted networks and poorer care resources when they reach old age (Grant & Wenger, 1993) than those without pre-existing health limitations. While it requires empirical and longitudinal testing, the above hypothesis, based on the literature, re-emphasizes the idea that those in the poorest health will tend to receive the least care.

Policy Implications

Regardless of the dire predictions for care network capacity over the long-term postulated by the literature, the findings of this study showed that, in 1996, Canadian adults with disability who were in good health, or who had large networks, were provided the greatest amount and variety of care while those

most at risk for inadequate care resources were those already in poor health or those with networks that were small or without proximate members. While there were fewer significant associations than expected, especially related to gender and relationship composition, network characteristics were able to predict both the provision and amount of all care tasks. In general, the finding of this study strongly contradict a key assumption of on-going health care policy reform that individuals with disability are able to rely on large networks of friends and family to provide them with care when needed (Brodie, 1999; Crichton & Jongbloed, 1998).

Furthermore, while care network size appears to be a key predictor of its capacity to provide care, a lack of broadly accessible policies to support family and friend caregivers does little to encourage or help sustain care network membership, especially as the burden of care increases and in light of the negative consequences experienced by caregivers (Keating et al., 1999). For example, because they are not guaranteed under the Canada Health Act, there is great variability and inequality in access to home care services which are key to helping sustain care in the community (Fast et al., 1999; Picard, 1999). The degree to which employment standards may support care network membership and the availability of supportive programs such adult day care and subsidies for health supplies also varies dramatically (Eales et al., 2001).

In addition, the few policies that are directed at caregivers in the community, such as the Caregiver Tax Credit, tend to be narrowly targeted to kin, co-resident or other 'traditional' caregivers so that they likely act as a disincentive for non-traditional care network members such as friends and neighbors (Eales et al., 2001). Other government policies may even have negative consequences for those who choose to participate in care networks. For example, Social Assistance or Employment Insurance does not assist those who leave their job in order to provide care while ongoing pension reforms may reduce the income of care receivers as well as the current and future income of caregivers (Fast et al., 1999).

Finally, home care policies increasingly are emphasizing nursing and personal care services over help with care tasks such as meal preparation or house cleaning (Aaronson, 2002). Greater accessibility to help with personal care from formal home care services might help to explain why, in comparison with other care tasks, the smallest proportion of the sample in this study was provided help with personal care despite being in generally poor health. However, formal services that provide help with every-day household tasks may be equally important for sustaining care-receivers and their care networks in the community (Keating, Fast Oakes & Harlton, 1996) and especially over the longterm as the burden of increasing care needs will tend to fall on smaller and smaller networks with a reduced capacity to provide care.

Summary

This study was a first step towards filling existing gaps in the research literature on care networks, as opposed to care dyads, and care provided to adults with disability as opposed to seniors or children. In general, it was shown that the characteristics of care networks are important for determining their capacity to provide different kinds and amounts of care. Overall, the findings suggest that Canadian adults with disability likely do not have networks with sufficient size and capacity to provide them with care over the long-term. As a result, findings re-emphasize the need for broad and accessible government policies to support family and friend care network members in order that adults with disability can remain active and independent in their community regardless of health status (FPTM, 2000).

The Government of Canada recently was provided a list of recommendations that would reduce costs to all family and friend caregivers and potentially support larger, more diverse and sustainable care networks. Highlights from these recommendations include reforming existing labor, income security and health policies to: respect the diversity in relationships between informal caregivers and care-receivers; broadening eligibility criteria to apply to caregivers regardless of residency, relationship, or income of the care-receiver;

and providing direct financial compensation to caregivers (Fast and Keating, 2001).

Implementation of these recommendations would go along way towards addressing the needs, improving the outcomes and enhancing the sustainability of care networks regardless of the gender or relationship of the caregiver or the age or disability of the care-receiver. By describing the characteristics and outcomes of networks caring for Canadian adults with disability who, for the most part, have been ignored by previous research and public policy (Salvatori, Sandys & Marcaccio, 1998), this study has provided a baseline for monitoring the potential and hopeful effects of policy reform.

Limitations resulting from the dataset and poor sample size, as well as additional but untested hypotheses present in the literature, also suggest the need for future and, especially, longitudinal research on care networks. Furthermore, while this study has contributed to an understanding of which network characteristics are important for determining care outcomes, it is not well understood how the interaction or configuration of characteristics may jointly affect the care that is provided. Therefore, a next step in the research of care networks for adults with disability would be classifying different types of networks and exploring how well identifying a care-receiver's network type would assist in predicting care outcomes (Wenger, 1997).

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